

NORTH CAROLINA DEPARTMENT OF HEALTH AND HUMAN SERVICES
DIVISION OF AGING AND ADULT SERVICES

Alzheimer's Disease Demonstration Grants to States Program

PROJECT C.A.R.E:
"Caregiver Alternatives to Running on Empty"
2007 - 2008

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ABSTRACT

The North Carolina Division of Aging and Adult Services supports this one year Alzheimer's demonstration project in collaboration with the Duke Family Support Program, Western Carolina Alzheimer's Association, Mecklenburg County Department of Social Services, Mission Hospitals and other key partners. The goal of the project is to increase quality, access, choice, and use of respite and support services to low-income rural and minority families caring for a person with dementia at home or within a hospital setting. The approach is to build upon prior successes and further efforts to create a more responsive, dementia-capable system of home and community-based care across the state. The objectives are to implement: 1) a national best practice model of consumer-directed respite services; 2) a new collaboration plan with local Aging and Disability Resource Connections (ADRC); 3) a new early onset dementia education and public awareness initiative; 4) an evidence-based system of data collection and evaluation; and 5) to establish a direct link to the local health care system through formal collaboration with a regional hospital. Expected outcomes are: 1) dementia caregivers will receive consumer-directed respite care and support specifically designed to meet their unique needs throughout the disease process; 2) a new database system will be in place to demonstrate the impact of the project at multiple program and policy levels; and 3) a new collaborative model for hospital-based respite support will be developed. The products from this project include: dementia-specific materials on hospitalization and emergencies, dementia-capable referral protocols for ADRC programs and a new program manual to assist with future program replication and expansion.

PROBLEM STATEMENT

Demography: Within the next ten years, as the first wave of baby boomers reaches the age of greatest risk for Alzheimer's, the number of people affected by dementia will increase dramatically. According to the most recent prevalence estimates, approximately 5.1 million Americans now have Alzheimer's disease, including at least 200,000 individuals younger than 65 with "early-onset" dementia (1). Alzheimer's is the seventh leading cause of death for people of all ages and the fifth leading cause for adults age 65+ (2). Between 2000 and 2004, Alzheimer's was the only leading cause of death in America that increased in frequency (by 32.8%) (3). In 2000, the state of North Carolina

ranked #10 among all states for having the highest number of older adults with dementia (4). North Carolina currently has over 150,000 older adults with Alzheimer's disease. By 2030, this number is projected to rise to over 294,000 (5).

Caregiver Health: The detrimental health effects of providing long term care to a person with serious illness or disability has emerged as a critical public health issue. More than one-third of caregivers continue to provide intense levels of care while suffering from poor health themselves (6). The health risks and burden of caregiving can hinder a person's ability to provide care, lead to higher health care costs and affect the quality of life of both the caregiver and the person receiving care (7). Caregivers are particularly vulnerable to severe exhaustion and stress-related illnesses which are among the most cited reasons for early institutionalization (8). Keeping family caregivers healthy and safe and strengthening their ability to provide quality care in the home for as long as possible is key to maintaining our nation's long term care system (9). This issue will become even more important as caregiver numbers increase.

Caregiver Burden: Dementia caregivers, in particular, are exposed to chronic stress that is persistent, uncontrollable, unpredictable and involves a high level of vigilance (10). This type of complex caregiving generates tremendous physical and psychological strain with little opportunity for adaptation (11). The progressive nature of Alzheimer's disease poses enormous challenges to caregivers. Individuals with dementia require increasing levels of assistance and will eventually need full-time care and continuous supervision for their safety.

One of out four dementia caregivers provides constant care— an average of 47 hours per week – often for years on end (12). More than half feel as if they are “on-call” 24 hours a day and find it necessary to reduce or end employment to fulfill the demands of caregiving (13). Caregivers of persons with dementia encounter more family conflict, care-related stress, serious health problems and a shorter life expectancy (14). They often experience profound grief and feelings of anger, guilt, fear and isolation. Nearly half (43%) are clinically depressed (15). These anxiety-inducing conditions often go untreated and unchecked because caregivers do not have the time or resources to manage them (16).

Need for Respite Support: To facilitate the care of loved ones at home, families need information, consultation and a range of health and support services, including respite care. Although family caregivers continue to identify respite as one of their greatest needs (17), it remains in short supply for all age groups or is inaccessible to the family

because of eligibility requirements, cost, geographic barriers, or the lack of culturally sensitive programs (18). Without adequate information, support and timely respite, families often suffer economically and emotionally, and caregivers themselves face serious health and social consequences. Respite care has been shown to reduce the likelihood of neglect and abuse, help sustain family care capacity, and prevent or delay costly out-of-home placements (19). This type of support benefits both the primary caregiver and the individual with dementia by enhancing quality of life, promoting better psychological health and preserving family relationships.

The 2007 Aging Services Plan and Long Term Services and Supports (LTS) Action Plan for North Carolina prioritizes the need to invest in family caregiving as the primary resource for long term care, thus reducing the risk for needing formal, publicly financed services. In order to strengthen the state's investment, North Carolina intends to create a flexible, coordinated, and consumer-directed care system that is responsive to the unique needs and preferences of individuals with dementia and their caregivers and more supportive of home and community-based services. Families must have access to "affordable, readily available, high quality respite care (20)" and other appropriate supportive services. This is critical to the success of developing an effective state delivery system.

Targeted Populations: The aim of the proposed demonstration project is to reach family caregivers who are not receiving services due to economic or geographical factors, racial isolation, or lack of available local resources. The project will focus on low-income, non-Medicaid eligible, rural, and minority populations in three targeted areas of the state. Project sites will be based in three locations: Charlotte, Winston-Salem and within an expanded site in Asheville. The Asheville-based site will increase its service area from six to ten counties to include Buncombe, Haywood, Jackson, Swain, Henderson, Polk, Transylvania, Rutherford, Madison and McDowell counties. In Charlotte, the demonstration program will serve Mecklenburg County, the largest metropolitan area in the state encompassing a high concentration of minority groups, predominantly African-American. In Winston-Salem, the program will intensify services to Forsyth, Surry, and Stokes counties. Forsyth County is also an area of the state with a large African-American community.

The four new counties to be served by the Asheville office were strategically selected. Jackson and Swain counties are among the most rural poor and minority western North Carolina counties. Approximately two-thirds of

elder residents have median incomes below \$25,000 (21). These incomes are usually “fixed” and rely on inadequate monthly Social Security payments. Haywood and Buncombe counties are retirement destination areas that will be hit hard by the growing numbers of people with Alzheimer’s disease. Between 1996 and 2020, the projected growth of the 65+ population in these two counties is significantly higher than the expected increase in the 65+ state population as a whole (22). The four new western counties were also selected to implement a new program component offering respite care and support services to dementia caregivers within a regional hospital setting and/or immediately upon discharge. The details of this new component are outlined in the intervention section of this proposal.

System Gaps: In North Carolina, multiple community agencies provide dementia services, but almost none are based on caregiver assessment and needs. Some services, such as in-home aide, are available in all counties, but usually not in sufficient quantity due to the inadequate funding and an ongoing shortage of direct care workers. Adult day services, a preferred respite option for many families, are only available in 57 of the state’s 100 counties, with a total of four centers offering specialized programs for individuals with Alzheimer’s disease (23). Funding for adult day services is limited, and waiting lists are long. Private pay services exist in most counties but the rates are cost-prohibitive for low and middle-income families.

In many counties, information on service contacts, availability and eligibility is difficult to access. In general, agency staff are only familiar with their own programs so referral to other services is very limited. Outreach efforts are also minimal or non-existent, especially when funding is scarce. Waiting lists are based on program goals that still do not prioritize or even address the needs and preferences of caregivers. Health care providers, often the first contact for families dealing with dementia, are not aware of services available through the aging and social service systems.

State Respite Funding: The value of respite services in North Carolina, as distinct from other forms of community support for families, has only recently been recognized. N.C. General Statute 143B-181.10 establishes and defines respite as part of the continuum of care administered under the auspices of the North Carolina Division of Aging and Adult Services (NC DAAS). The statute does not provide separate funding but establishes several forms of respite care that can be supported by state and federal funds. Although the service definition for in-home care includes the

possibility of respite, providers traditionally prioritize persons who live alone, rather than caregivers, and limit their services to personal care or homemaker services.

Home and Community Care Block Grant (HCCBG): The HCCBG, comprised of Older Americans Act and state funds, supports home and community-based services for older adults. Respite can be in the form of adult day services, group respite, residential, or in-home care. Based on a formula, each county receives funding, and a county planning committee for aging services determines which services will be provided. Some counties choose not to use funds for respite care. Although other counties may fund it, the amount is not sufficient and waiting lists are long.

Family Caregiver Support Program (FCSP): The State FCSP is funded through Title III E of the Older Americans Act. The portion of these funds designated for respite is limited and, in attempting to serve all types of family caregivers, spread very thin. In addition, the FCSP does not contain a dementia-specific component.

Medicaid Waiver Program: The State Community Alternatives Program (CAP) provides an excellent array of home and community-based services, but North Carolina has a more restrictive income and resource level than any other state in the nation. Therefore, access is limited to the very poor, with no savings and little work history on which to base Social Security benefits.

Systems Change Progress: Despite the existing service gaps and barriers identified above, North Carolina has made considerable progress over the past five years through a variety of new, innovative state programs and initiatives aimed at creating a better system of care for all populations in need of support. These efforts include consumer-directed services, NC FCSP, Aging and Disability Resource Connections (ADRC), CMS Systems Transformation Grant Programs, and the new Alzheimer's demonstration program. In response to recent planning events and technical support provided by the Alzheimer's Disease Demonstration Grants to States (ADDGS) National Technical Assistance Center, preliminary plans are also in place to pursue steps toward the initial development of a new State Alzheimer's Plan for North Carolina.

GOALS AND OBJECTIVES – *See Work Plan Grid

PROPOSED INTERVENTION

The proposed intervention for the North Carolina Alzheimer's demonstration program is Project C.A.R.E., "Caregiver Alternatives to Running on Empty". Project C.A.R.E. uses a family consultant model to provide consumer-directed respite care and comprehensive support to dementia caregivers. The goal of the program is to increase quality, access, choice, and use of respite and support services to low-income rural and minority families caring for a person with dementia at home or within a hospital setting. Through the integration of dementia-capable services and the development of family-centered and caregiver-focused community care networks, Project C.A.R.E. intends to create a seamless, coordinated delivery system that is responsive to the needs, values and preferences of Alzheimer's families.

The Alzheimer's demonstration program will be administered through the NC DAAS with expert consultation and technical assistance provided by the Duke Aging Center Family Support Program (Duke). Project C.A.R.E. will be implemented at the local level through Family Consultants employed by and/or supported through the Alzheimer's Association – Western Carolina (WC) Chapter. The Mountain Area office of the WC Chapter will serve as the project training and data management center for all new and existing program sites and staff. [*See Figure 1]

Project C.A.R.E. Family Consultants will visit the homes* of referred or self-referred dementia caregivers in crises. The Consultants will offer timely individualized assessment, guidance, counseling, support, advocacy, coaching and education for family caregivers. Their aim will be to match families with the most appropriate and preferred local respite and community services tailored to the unique context of care and family needs. Through Project C.A.R.E., dementia caregivers may spend up to \$2000 a year toward respite services. Families will be able to choose among a full continuum of consumer-directed care options, including adult day services, group respite, private or agency in-home care, and overnight residential respite. [*See Attachment A]

The Project C.A.R.E. Family Consultants will employ a family-centered, home-based assessment intervention. In-home assessments are preferred because they are responsive to caregiver time and energy constraints. During the home visits, the Consultants will: 1) assess the family care environment; 2) identify the needs and preferences of

* *Note: "Home" visits or "in-home" assessments may take place in the hospital setting when applicable.*

both the caregiver and the person with dementia; 3) facilitate discussion and mutual understanding among family members; 4) connect the family with community resources; and 5) ensure the provision of quality respite care and support services. The personalized approach of the Family Consultant is intended to foster family trust, offer individualized caregiving and coping skills, and encourage caregiver self-care. Project C.A.R.E. aims to help families accept the value of quality dementia-specific respite services and feel empowered to make self-directed, informed decisions about care.

The Project C.A.R.E. model builds upon, enhances and sustains existing home and community-based services. The Family Consultants will use local providers to deliver respite care while offering a direct link to the expertise and resources of the Alzheimer's Association. Project C.A.R.E. will also open doors to the NC FCSP, ADRC, Hospice and other caregiver-focused initiatives creating a strong network of community support for Alzheimer's families [*See Figure 2]. This comprehensive system of care will strengthen the family's capacity to manage the diverse challenges inherent in caring for a person with dementia.

Project C.A.R.E. was originally created in 2001 by Alzheimer's experts from the NC DAAS, Duke and the WC Alzheimer's Chapter. The first pilot project was funded through the federal AOA-ADDGS Program and initially tested in four rural counties and two urban counties with large minority populations. The first demonstration was very successful in reaching targeted populations, delivering culturally competent services, and fueling community collaboration to support Alzheimer's families. In April of 2004, Project C.A.R.E. was recognized by the Southeast Regional Geriatric Best Practices Initiative and received a best practice award for "Developing Quality Caregiver Support and Respite Programs".

In July 2004, DAAS received a three-year federal grant to enhance the Project C.A.R.E. design and expand the program into four additional rural western counties. It was during this demonstration that Project C.A.R.E. made considerable progress building and strengthening community and state partnerships, heightening awareness of the unique needs of dementia caregivers and clearly demonstrating the value of and critical need for consumer-directed, dementia-specific respite programs across the state. The program established community ownership, secured supplemental funding from local FCSP's and private foundations, and received increasing attention and support from

county planners, advocates and legislative groups. By 2005, Project C.A.R.E. was recognized as a national best practice model by the AOA-ADDGS Program and RTI International for "Implementing Systems and Sustained Change in Long-Term Care". That same year, Project C.A.R.E. received a "National Innovative Program Clearinghouse Award" through the National Alzheimer's Association and was featured by the Association as a national model for home and community-based care coordination at the National Conference of State Legislators.

This momentum led to a formal recommendation by the NC General Assembly Study Commission on Aging to allocate state funds to sustain the existing program sites— working toward the ultimate goal of statewide implementation. An annual appropriation of state funds for Project C.A.R.E. would leverage new federal grant funds to further expand the program and test new pilot sites in other areas of the state. To date, bills have been introduced into the House and Senate by members of the Study Commission on Aging requesting state funds for Project C.A.R.E. [*See Appendix]. These bills are sponsored by twenty-six Representatives and six Senators and are supported by NC Senior Tar Heel Legislators, NC AARP, AAA's and other local advocacy groups as well as the NC Aging Services and LTS Plans. The final outcome of state funding decisions may not be determined until next fiscal year. Efforts to further expand Project C.A.R.E. across the state will be considerably strengthened if North Carolina is eventually able to secure current service areas through state funding.

Of special note is the recent ratification of a new bill addressing the issue of respite services in North Carolina [*See Appendix]. On May 2, 2007, the NC General Assembly mandated the NC DHHS to conduct a formal study on respite care and to recommend ways to improve the current respite care delivery system. In addition to Medicaid related issues, the Division of Medical Assistance, Division of Facility Services, DAAS and other key groups will focus on the availability, provision, need and availability of respite in North Carolina and identify potential delivery models for the State. Findings will be presented to the NC Study Commission on Aging before March 1, 2008. Project C.A.R.E. staff and partners have already been selected to serve on the NC Respite Care Study Workgroup and will be able to provide valuable insight through the experience of Project C.A.R.E., offer a national best practice model for respite care delivery and promote the integration of dementia-specific services into future state respite care systems.

Outreach: Culturally sensitive outreach strategies will be implemented within targeted counties to inform rural and minority families, local providers and community agencies about Project C.A.R.E. These strategies will be based on lessons learned through the success of previous demonstrations (24). The WC Alzheimer's Chapter will publicize Project C.A.R.E. in quarterly newsletters and refer callers from the Helpline. The Family Consultants will create program announcement flyers and brochures for distribution at support groups, health fairs, workshops, meetings and other educational and public awareness events. The flyers will be mailed to community health centers, physicians, pharmacists, hospitals, churches, senior centers, provider agencies, and others. The Family Consultants will make outreach visits and presentations on Project C.A.R.E. to county planning committees, caregiver coalitions, regional advisory councils, ADRC staff, Area Agencies on Aging (AAA), departments of social services, faith-based organizations and other key groups. Collaboration with the Mission Hospitals Dementia Responsive Care (DRC) Program will also be a critical component to the outreach plan [*See page 11].

Training: Initial program orientation and basic dementia care training will be conducted by the Family Consultants and Alzheimer's Association staff. Provider agencies, client families, ADRC personnel, AAA's, Hospice, volunteer groups and other community partners will be offered this training at no additional cost. The training will include an overview of Project C.A.R.E. and general information on Alzheimer's disease and related disorders, communication skills, challenging behaviors, and techniques for reducing resistance to assistance with personal care tasks. Other sections of the training, specific to respite providers, will focus on the Project C.A.R.E. referral process, assessment of family and caregiver needs, consumer-directed use of respite care, and procurement of payment for services. Program orientation and basic training will be conducted regularly during the first six months within each new targeted county and as needed thereafter for any new providers and/or project participants. More in-depth dementia-specific training is available on an ongoing basis through the local Alzheimer's Association and Duke.

Through collaboration with Project C.A.R.E. and Mission Hospitals DRC Program, the WC Chapter's Mountain Area Regional Program Director will launch a new public awareness and education initiative within Buncombe County and surrounding areas. The initiative will be two-fold. It will, first, focus on raising awareness of early onset dementia through community and hospital-based education and support activities. Second, the Chapter and key partners will

conduct a series of caregiver training workshops on how to prepare for emergencies and hospitalization. The training will emphasize the importance of planning ahead as well as available home and community-based care options and resources. Both components of this new initiative will involve participation from a variety of local organizations such as Memory Care, Hospice, and regional Family Caregiver Support Programs. Revised editions of *Hospitalization Happens* and *Acute Hospitalization and Alzheimer's Disease* will be distributed to participants in addition to new publications on early-onset dementia upon release from the National Alzheimer's Association.

Research Support: Over twenty years of caregiver intervention research has generated significant, clinically relevant outcomes and effective strategies for helping family caregivers (25). Although caregiving can have a negative impact on a person's health and well-being, research demonstrates its effects can be alleviated through long-term supportive programs (26). The Project C.A.R.E. model relies heavily on these research findings to guide and support its practice and further efforts to enhance the program's overall design (27).

According to recent studies (28), the most effective caregiver interventions are individualized, flexible, home-based and consumer-directed. Programs should be comprehensive— offering respite care, counseling, care consultation, emotional support, family caregiver assessments, dementia-specific information, caregiver education and connections to strong social support networks. Other recommendations include financial assistance, home modifications and incorporating measures to ease the “suffering” of the person receiving care.

Evidence-based support programs have proven effective in relieving caregiver depression and stress over a long period of time (29). These interventions also reduce care-related illness, family conflict and isolation while improving satisfaction with social supports and enhancing day to day coping skills (30). Additionally, institutionalization can be delayed or prevented without overburdening family members (31). It is critical for ongoing support and assistance to be available throughout the caregiving process in order to protect the health and well-being of family caregivers and help them effectively manage the extreme demands of providing long term care.

SPECIAL TARGET POPULATIONS AND ORGANIZATIONS

The Project C.A.R.E. model has documented success in reaching underserved families, with a special emphasis on targeting rural and minority communities that have limited knowledge of and access to dementia-specific respite

care and support services (32). Priority will be given to persons in greatest social and economic need. The new demonstration proposed here provides an opportunity to build upon a strong foundation. The increasing support and involvement of community and state partners as well as local advocacy groups fuels the momentum to expand Project C.A.R.E. into new areas of the state. The organizations that will provide assistance with program planning, outreach and implementation are described below.

Mission Hospitals Dementia Responsive Care (DRC) Program: In 2002, Mission Hospitals and the Western Carolina Alzheimer's Chapter received a grant from the Duke Endowment to develop a new program to improve care for hospital patients with Alzheimer's disease. The grant funds supported the development and implementation of an acute care based initiative called "Dementia Responsive Care." At the end of the three year grant period, Mission Hospitals recognized the success and importance of the project and provided funding to sustain the program. Since 2005, Mission Hospitals has continued to support further development of the DRC Program. The National Alzheimer's Association's Public Policy Office cites this exemplary program as the only hospital demonstration fully funded and integrated into an existing hospital system.

Mission Hospitals DRC Program staff identified respite care as one of their greatest unmet needs for family caregivers of persons with dementia. Through partnership with Project C.A.R.E., the DRC Program will be able to provide additional support to caregivers by linking families directly to a Project C.A.R.E. Family Consultant to receive immediate consultation and respite care assistance. Depending on individual needs and preferences, caregivers can use Project C.A.R.E. services to help them through the hospitalization experience and/or to ease the transition from the hospital setting back into the home environment. As hospitalization is often a trigger to institutional placement (33), an effective and timely caregiver intervention could offer an alternative to help families who prefer to have their loved one return home following discharge rather than the more typical post-hospital nursing home placement. This new collaboration with Mission Hospitals DRC Program will serve as a model for how Project C.A.R.E. can be utilized to support and strengthen a regional hospital system of care. [*See Attachment B]

Aging and Disability Resource Connections: In 2004, the NC DAAS was awarded an Aging and Disability Resource Center grant from the Administration on Aging (AOA) and the Centers for Medicare and Medicaid Services

(CMS) to establish a new statewide information and assistance infrastructure. To date, North Carolina effectively implemented two Aging and Disability Resource "Connections" (ADRC) pilot programs in Forsyth and Surry counties, both of which are also served by Project C.A.R.E. The ADRC Program has also started the initial implementation phase of the "NC careLINK", a web-based portal for all state health and human services as well as statewide expansion of a volunteer benefits counseling initiative. [*See Attachment C]

Through close collaboration with Project C.A.R.E., North Carolina will begin to take steps toward developing an ADRC program that is dementia-capable. Collaboration activities will include:

- Duke and the local Alzheimer's Association will provide specialized training and educational resources to ADRC staff to help increase the capacity of the ADRC program to respond to the needs of individuals with dementia, their families and their caregivers;
- Project C.A.R.E. staff will participate in ADRC advisory committees and evaluate the dementia-related data and web links within the NC careLINK to insure the information and/or resources are adequate, comprehensive and relevant;
- Duke, Project C.A.R.E. staff, and the Alzheimer's Association will assist the ADRC program in establishing formal pathways and developing extensive referral protocols to help ensure that dementia families have seamless access to appropriate and timely services and supports from earlier recognition and diagnosis of a dementia through palliative and end of life care;
- The ADRC's will heighten the visibility of Project C.A.R.E. and increase local access to dementia-specific respite care, training, education and support services.

By working together, Project C.A.R.E. and the ADRC program will maximize resources to provide a comprehensive and coordinated array of services aimed at empowering individuals and family caregivers to make informed choices and to streamline access to long-term services and supports.

Family Caregiver Support Program: The Project C.A.R.E. Family Consultants will build and strengthen working relationships with regional AAA Family Caregiver Resource Specialists in order to identify community resources, fill gaps in service delivery, and assist caregivers of persons with dementia in need of respite care and dementia-

specific support services. The Family Caregiver Resource Specialists (FCRS) will: 1) assist with the assessment of need in targeted counties; 2) provide a current inventory of home and community-based resources; 3) increase public awareness of and local involvement in Project C.A.R.E. through ongoing communication and consultation with AAA service provider networks and other key community groups; 4) link dementia caregivers to Project C.A.R.E. through community outreach efforts; and 5) assist with identifying aging and adult services staff, health care professionals, providers, volunteers, faith-based groups and family caregivers in need of dementia-specific training and education.

CMS Systems Transformation Grant: In February 2006, the North Carolina Department of Health and Human Services (DHHS) began a “Connect the Dots” initiative— a conscious effort to link various long term services and supports (LTS) grants and other systems change activities within the Department. A core planning group was formed and is developing a LTS action plan. Staff from Project C.A.R.E. actively participates in the core planning group as well as the “Connect the Dots” initiative and helped develop the LTS strategies and action steps related to family caregiver support, respite and case management, including the work of Project C.A.R.E. In September 2006, NC DHHS was awarded a five-year CMS Real Choice Systems Transformation grant. The purpose of this grant project, NC ACE (“North Carolina Access and Choice made Easy”), is to implement broader changes in the state systems infrastructure to support continued development of quality community-based service options that maximize individuals’ independence, dignity, choice and flexibility.

The collaborative spirit that began between Project C.A.R.E. and the Real Choice Systems Change grant will certainly continue with NC ACE. Alzheimer’s caregivers are represented on the NC ACE stakeholder advisory committee. There is also mutual participation in meetings between grant staff. Most importantly, Project C.A.R.E.’s plan to integrate consumer-direction into the available respite options for all of its targeted counties coincides perfectly with the NC ACE goal to expand the self-direction option in North Carolina.

Duke Family Support Program: The Duke University Center for the Study of Aging Family Support Program has extensive experience in the field of Alzheimer’s and dementia care and a wealth of nationally-recognized educational products and resources. The Director of the Duke Family Support Program helped design the original Project C.A.R.E. model and has been closely involved in refining the program through planning, evaluation and technical

support. For the new demonstration project, the Director and staff will continue to provide professional consultation services as well as ongoing training and education. [*See Attachment D]

***MEASURABLE OUTCOMES – *See Work Plan Grid**

Program Benefits: The experience of Project C.A.R.E. in North Carolina is and will continue to provide valuable information on unique non-duplicative services within strategically targeted communities. The family consultant model is flexible and straightforward and has proven success in effectively serving traditionally hard to reach and inadequately served populations (34). This model can be easily adapted to different settings and used to target other special needs populations. North Carolina could serve as a resource by providing information, training and educational materials on consumer-directed services, dementia-specific respite care and other elements unique to the Project C.A.R.E. design. This type of support would be especially useful to other communities and states interested in replicating the intervention and/or utilizing a grassroots approach to program outreach and development.

Long term projections for the future of Project C.A.R.E. are positive as evidenced by a growing base of local, regional and state support, increasing demand for Project C.A.R.E. services and an escalating intensity of grassroots advocacy efforts. The proposed expansion into four new counties, with additional partnerships and resources to increase effectiveness, will only result in a more enhanced and cohesive program design. Project C.A.R.E. will also continue to develop useful educational products and resources that are readily available and applicable to a broad range of professionals in the field of health care, aging, dementia and/or caregiver support.

PROJECT MANAGEMENT: [*See Figure 1]

Grant Administration: Karisa Derence, DAAS Alzheimer's Support Specialist, will serve as the State Project Director. Ms. Derence will spend at least 60% of her time on the demonstration program. In addition to performing grant administrative activities, she will be involved with the on-going technical assistance and oversight of the Project C.A.R.E. Family Consultants regarding the proposed work plan and the overall project implementation. Ms. Derence and the Duke Family Support Program Director will conduct site visits with the Consultants and Alzheimer's Chapter staff at each of the three project sites. When feasible, the on-site visits will be scheduled to coincide with local committee meetings and/or training events. Ms. Derence will also conduct conference calls and meetings with project

staff and key collaborators. She will assist with public awareness and program education through local, state and national meetings and conferences. Additionally, Ms. Derence will work collaboratively with and provide updated grant information to the NC FCSP, ADRC, ACE and members of the NC Respite Care Study Workgroup.

Duke Family Support Program: Lisa Gwyther, Director of the Duke Family Support Program, will provide expert consultation and technical assistance to the Project C.A.R.E. Family Consultants, AAA Family Caregiver Resource Specialists, ADRC and NC ACE staff, NC Respite Care Study Workgroup, respite providers and referral agencies. Ms. Gwyther will work directly with Project C.A.R.E. staff via telephone, e-mail, and on-site visits. She will also assist with training and public awareness efforts through presentations at state, regional and national conferences. Ms. Gwyther will work closely with Project C.A.R.E. and DAAS staff in the development and review of new educational products and state policies related to dementia care and family support.

Family Consultants: Four full-time Family Consultants will be responsible for implementing Project C.A.R.E. within the targeted service areas. The Family Consultant in Charlotte, Marsha Ghent, will be employed by the county department of social services and supported by the Western Carolina Chapter's Piedmont office. Ms. Ghent will also work part-time as the local Family Caregiver Resource Specialist. The Family Consultants based in the Winston-Salem site (Wilhelmenia Pledger) and Asheville sites (Kether Abeles; TBD) will be employed and supervised by the Chapter's Mountain Area office. The Asheville Family Consultants will work in close collaboration with the Mission Hospitals DRC Program. The Family Consultants will also work closely with regional FCSP's and the Alzheimer's Association for ongoing caregiver-focused and dementia-specific training, education, and resource needs. The Family Consultants will assist with public awareness and community education events, work with local caregiver and advisory committees, and collect program data that will be analyzed and disseminated to promote sustainable changes within the state health care and service delivery system.

Training Support and Program Development: Len Erker, Director of Respite and Mountain Area Policy for the WC Alzheimer's Chapter, will serve as the lead trainer and supervisor for Project C.A.R.E. He will develop a Project C.A.R.E. program manual as well as an intensive orientation and training plan for all new Family Consultants. Mr. Erker will provide ongoing training support and technical assistance to Consultants through site visits, conference

calls, telephone and email correspondence. He will also assist with program planning, policy development, grant writing, public awareness and educational activities.

Data and Finance Management: A new position will be created and based in the Mountain Area office of the WC Chapter to address the critical need for data collection, analysis and evaluation. Responsibilities will also include financial management and coordination of provider contracts, invoice billing and ongoing monitoring of client funding levels for respite care. This new position will significantly increase the service capacity of the Chapter and help prepare for future program expansion.

AAA Family Caregiver Resource Specialists (FCRS): The fourteen counties that will be targeted by Project C.A.R.E. cut across five AAA regions. The FCRS's involved in the implementation of the demonstration project will be Cindy Miles (Region A), Carol McLimans (Region B), Michelle Templin (Region C), Dottie Lyvers (Region I), and Marsha Ghent (Mecklenburg County). In all three Project C.A.R.E. service areas, the FCRS's will help identify families in need of dementia-specific respite care and assist with community training and public awareness initiatives.

The FCSP Director at the state level will also be closely involved in the Alzheimer's demonstration project. The Director's role will include working with AAA's to ensure that populations with the most critical needs are prioritized and to identify gaps and barriers in services at the state and county level. This support will be beneficial to Project C.A.R.E. both now and in the future when looking to further replicate and expand the project across the state. Additionally, the FCSP Director continually promotes the significant role of family caregivers in providing long term care at public forums, statewide meetings, and educational conferences. These activities reinforce the importance of consumer-directed programs like Project C.A.R.E. and the critical need for respite and ongoing family support.

Mission Hospitals Dementia Responsive Care (DRC) Program: The DRC Coordinator, Nancy Smith-Hunnicutt, will serve as the primary link between Project C.A.R.E. and Mission Hospitals DRC Program. Ms. Smith-Hunnicutt will work closely with the Project C.A.R.E. Family Consultants and local Alzheimer's Chapter staff in Asheville through mutual referrals, client tracking and follow-up; ongoing exchange of information and educational resources; collaborative public awareness and dementia training initiatives; and by sharing established community care networks.

EVALUATION

With the intent to develop a comprehensive and well integrated evaluation system that provides useful and relevant information to program staff in real time, Project C.A.R.E evaluation will be shaped by two guiding principles:

1) a good evaluation system provides quality programmatic feedback to State and local program staff while facilitating strategic planning for program development, implementation, management, and growth; and 2) a well developed evaluation framework is anchored in good science and theory, and mirrors the complex and changing realities of program planning and implementation.

Project C.A.R.E. has identified an evaluation tool which will be modified to track the data requirements, both direct care as well as other ADDGS services data, as outlined in the current RFP. This evaluation system, Progress✓Check, was first developed by the NC Division of Public Health to track policy, environment, and systems change data to meet the evaluation requirements for several CDC funded programs. The system tracks the development of a program as it progresses from groundwork stage (i.e., staff training, community needs assessment, planning products, new partnerships), to action phase (i.e., capacity building, community services, action towards environment, policy, and systems change) and finally, to achievements and accomplishments (i.e., environment, policy, and systems change outcomes, media coverage, newly generated resources as an outcome of previous work). The Progress✓Check System tracks events and activities linked to local program objectives and gathers credible evidence to justify conclusions about program planning. It is based on the theoretical framework provided by Fawcett et. al. and CDC in the seminal publication ⁽³⁵⁾ "Evaluating Community Efforts to Prevent Cardiovascular Disease" but has a wider applicability that goes beyond chronic disease and public health.

The Progress✓Check System: 1) helps program staff make data based decisions on program planning and development by providing easily accessible automated reports on local data; 2) documents local stories and successes that can be celebrated and shared with others; 3) helps the state track local environment, policy, and systems change efforts over time; 4) provides information on local programs to ensure accountability for funds received; and 5) provides process, impact, and outcome information for documenting performance and accomplishments to support continued or expanded funding.

The greatest strengths of Progress✓Check are its: 1) simple, user-friendly interface that allows for easy and intuitive data entry; 2) flexibility to adapt to the unique needs of different programs with relative ease; and 3) ability to generate automated reports that provide guidance to program staff in real time. The current system will be modified to adapt to Project C.A.R.E. program requirements.

The system revisions will be conducted under the guidance of an advisory committee which will include the State ADDGS Project Director, a research consultant from the UNC Center for Aging Research and Educational Services, and the Lead DAAS Planner and Evaluator. While the Project Director will ensure fidelity to programmatic issues, the others will oversee Progress✓Check revisions to customize it for Project C.A.R.E. The committee will also work with the programmer who designed the original system to implement the changes needed for Project C.A.R.E.

Extensive training and technical assistance will be provided to local, regional, and state program and evaluation staff on the use of the system. Plans also include the creation of a Progress✓Check manual to provide guidance and documentation. Once the system has been modified to reflect the program requirements of Project C.A.R.E., it will provide data not only for direct services but also for organizational, community, public policy, and systems level changes that can impact individual behaviors and risk factors in communities. The evaluation plans reflect a strong commitment from Project C.A.R.E. to build an evaluation component that is not only grounded in good science and theory but also provides useful and relevant feedback towards strategic planning and program growth. These plans are very much in line with the ADDGS Program's vision of using data for effective program planning and growth.

DISSEMINATION

Due to the success of previous Alzheimer's demonstration programs in North Carolina and the increasing demand for Project C.A.R.E. services in other counties, channels for disseminating information are already in place. Having an established system for communication will help expedite the delivery of new program data on a regional, state and national level in an effective and efficient manner. Key collaborators, advocacy groups and legislators are eager to learn about the implementation of Project C.A.R.E. in new and existing service areas in order to assess the impact on underserved populations, the feasibility of further program expansion, and the potential for sustainable systems change across the state. In an effort to increase program visibility and state support, presentations on the progress of

Project C.A.R.E. and evaluation findings will be made to the NC DHHS Office of LTS, DAAS, and other interested Divisions; the NC Senior Tar Heel Legislature, NC AARP, Governor's Advisory Council, AAA's, NC Respite Care Study Workgroup, and the NC General Assembly Study Commission on Aging.

Other Dissemination Activities: The State Project Director, Family Consultants and key grant staff will focus on establishing and strengthening local partnerships and building sustainable networks of community support within all targeted counties. In an effort to facilitate ongoing communication and encourage community involvement, Project C.A.R.E. Family Consultants will conduct general dissemination and update activities throughout the demonstration period. These activities will include: 1) reporting to local caregiver, planning and advisory committees to assess project progress and impact; 2) distributing program materials and educational resources; and 3) presenting project findings to interested community agencies, faith-based groups, health care providers and conference audiences.

DATA COLLECTION

All Project C.A.R.E. staff and key partners will comply with state and federal data collection protocol and reporting requirements through the Progress✓Check System. DAAS is fully committed to the program evaluation process as a critical component of success. Evaluation plans are in place to ensure an environment of continuous improvement.

ORGANIZATIONAL CAPABILITY

NC Division of Aging and Adult Service (DAAS): Established as a division in 1977, DAAS is the state agency responsible for administering the activities developed under the federal Older Americans Act and the programs for older and disabled adults funded by the North Carolina General Assembly. Sections within DAAS include: 1) Planning, Budget, and Systems Support; 2) Service Operations; 3) Elder Rights and Special Initiatives; and 4) Adult Social Services. The Division manages the National Family Caregiver Funds (Title III E of the Older Americans Act) as well as a variety of other federal and state initiatives. The Division was also a former participant in the AOA-ADDGS Program. This demonstration grant will be housed within the Service Operations section, whose services include Nutrition, Transportation, Housing, Senior Centers, In-home Aide, and Adult Day Programs.

Alzheimer's Association - Western Carolina Chapter: The Western Carolina Alzheimer's Chapter has been in operation for 25 years. The Chapter serves as an advocate for individuals with dementia and provides information,

education, and training to family and professional caregivers. Through additional staff support, the Chapter has an increased capacity to serve its regions. The Chapter facilitates 61 support groups throughout a 49 county service area. In FY '05-06, the Chapter served a total of 25,742 individuals through outreach and training alone.

Mecklenburg County Department of Social Services (DSS): The Mecklenburg County DSS was originally established in 1919. Over the years, community development grants, Older Americans Act funding and county funds have allowed the expansion of services throughout the county. There are currently more than 1170 employees— 324 of these staff members work in the Services for Adults Division (SFA). The SFA annual budget is \$22,000,000+. Current case loads for SFA programs total 63,512 for Adult Medicaid, APS Referrals, and In-Home Aide Services and 1,178,303 for Nutrition and Transportation.

Duke Family Support Program: The Duke Family Support Program has been providing dementia-specific training, consultation and technical assistance for the state since 1984. The program has developed numerous publications and video resources that are used across the nation. As one of the oldest caregiver-focused state programs, staff at Duke, with access to academic research and policy expertise, can focus simultaneously on macro- and micro-aspects of this demonstration project.

Area Agencies on Aging: Area Agencies on Aging (AAA) established through the Older Americans Act and designated by DAAS, facilitate and support the development of programs to address the needs of older adults and promote their positive civic and social engagement. In North Carolina, there are 17 AAA's located within regional Councils of Government. Their primary responsibilities include: 1) advocacy; 2) planning; 3) program and resource development; 4) information brokerage; and 5) funds administration and quality assurance.

Mission Hospitals: Mission Hospitals is the regional referral center for Western North Carolina and the adjoining region. Mission is a JCAHO accredited, not-for-profit, independent community hospital system based in Asheville. Mission is licensed for more than 800 beds and bassinets. The medical staff includes more than 650 physicians in over 50 specialties. Mission employs nearly 6,000 employees.

REFERENCES & VITAE FOR KEY PROJECT PERSONNEL: [*See Appendix]

LETTERS OF COMMITMENT FROM KEY PROJECT PARTICIPANTS: [*See Appendix]